

Report of the
Board of Regents

National Library of Medicine
Long Range Plan

A Global Vision for the National Library of Medicine



U.S. Department of Health and Human Services
Public Health Service
National Institutes of Health

September 1998

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FOREWORD

Today, we are at the doorway of a new era for humanity; a new millennium stretches before us. The nation's investment in scientific research has created a revolution in the biological, medical, and material sciences unique in human history. Information and computer technology holds the promise of bringing new knowledge to billions of people across our globe in ways undreamed of even a short time ago. We now have the opportunity to provide timely and reliable access to health information resources that meet the highest standards of quality. This has always been the underlying goal of the National Library of Medicine. The recommendations of the Long Range Planning Panel on International Programs chart a most challenging course of action for the Library, one of leadership that is founded on partnership with the world's nations and peoples.



On this day, the Board of Regents of the National Library of Medicine unanimously and enthusiastically approves for incorporation in the NLM Long Range Plan the report of its Planning Panel on International Programs.

Michael E. DeBakey, M.D.
Chair, NLM Board of Regents
Chancellor Emeritus
Olga Keith Wiess and
Distinguished Service Professor of Surgery
Director, DeBakey Heart Center
Baylor College of Medicine
Bethesda, Maryland
January 27, 1998





THE WORK OF THE PLANNING PANEL

The National Library of Medicine is in the path of a whirlwind of changes. Many of these are forecasted in the vision of biomedicine in the coming millennium elsewhere in the pages of this report. As the largest medical library in the world, NLM's collection of more than 5 million items - books, journals, technical reports, manuscripts, microfilms, and pictorial materials- are an invaluable source of literature covering all aspects of health from the basic sciences to healing and prevention of innumerable afflictions suffered by human beings. In addition NLM houses special databases of information from which knowledge is constantly being generated, for example in worldwide collaborations assembling the structure of biological molecules. Presently, the most important of these involves the structure of the human genome.

NLM has been a pioneer in the creation and stewardship of computer-driven systems allowing users all over the world ready access to these databases and means to keep abreast of a very large number of papers and other reports from the world's community of health sciences. Its major communication medium is becoming the Internet, with tools not only to search the literature and databases, but also to link to an ever-expanding variety of sources, including electronic versions of complete journals. NLM's expertise in high performance computer technology is constantly adapting to an essential role in the global network which will be the nature of scientific exploration in the next hundred years. A greater flow of information will more strongly link medicine and the sciences, not only biomedical and behavioral, but other physical, chemical and social disciplines in the quest for better understanding of human beings and their relationships to the other forms of life sharing the planet Earth.

America has contributed generously to the advances in science and medicine in this century. The world's scientific and medical institutions must attempt to be prepared for the greater challenges and opportunities of the coming millennium. For this reason, the Board of Regents of the National Library of Medicine has asked the Director to empower a panel to develop a Long Range Plan for the international activities of the NLM. In doing so, the Director chose four questions to provide contours along which the plan should be developed. Stated below is my view of the answers the Planning Panel gave to these questions.

The first question was: *Does NLM have an international program?* When the Congress created NLM in 1956, the charge provided in the National Library of Medicine Act



read, in part, "to assist the advancement of the medical and related sciences, and to aid in the dissemination and exchange of scientific and other information important to the progress of medicine and the public health." Quickly capitalizing on the example of its predecessor, the Library of the Surgeon General of the Army, which had made the *Index Medicus*, the first compilation of the world's medical literature, the NLM provided the first computerized access to the Index Medicus. The Library then provided its computerized database to numerous international centers in exchange for abstracts of foreign literature and assistance in translation. Mainly because of the worldwide nature of medicine and its related sciences, the Library has thus beneficially supplied its users the essential international connections from the beginning. These international relationships

have been of steadily growing significance to both American and world medicine. Indeed, the increasing globalization of knowledge has made it clear that the domestic and international functions of the NLM are not separable.

Its second question was: *With what countries should NLM seek more relationships?* The recent enhanced accessibility of MEDLINE directly from NLM via the Internet presses the NLM to re-examine these older relationships. A broader reach is needed, however. In making new partnerships, the NLM will have great opportunity, but must match its comparative advantages with the needs of particular countries or regions, requiring NLM to be cognizant of the enormous diversity of this world, in terms of culture, language, health practices, technologies and economies. As expansion of international programming is necessary for NLM, so must the Library be aware that there is no single philosophy, product, or pricing that is likely to meet the needs of every country or region.

What kind of information should be of interest to NLM? There is no question that databases developing from cooperative international research, such as the sequencing of genes, and the extension from structure to function, have a high priority. The conversion of in-

"TO ASSIST THE ADVANCEMENT OF THE MEDICAL AND RELATED SCIENCES, AND TO AID IN THE DISSEMINATION AND EXCHANGE OF SCIENTIFIC AND OTHER INFORMATION IMPORTANT TO THE PROGRESS OF MEDICINE AND THE PUBLIC HEALTH."

formation to new knowledge is one of the functions in which the great libraries can play an indispensable role. The need for access to the reports of medical and scientific study, however, continues to be paramount for a larger audience. Quality and peer review of such reports are matters on which the users place a high premium. At the same time, there will be regions of the world or





other cultures or other international databases to which linkages can have considerable value. Means to link such reports and sustain a world-view has been one of the challenges to the panel.

What new technology must NLM be prepared to use or improve in the fulfillment of its mandate? The Panel was thoroughly briefed on the uses and growth of electronic publishing, the progress of the next generation of the Internet, digitization of data, the use of satellites to reach remote areas and the guesses of what likely new technological inventions will arrive to test the Library's ability to cope. The panel concluded that pressures to

diminish the role of the printed page will continue and that no one can predict what changes in information technology-given its estimated year-and-a-half turnover time-will bring. For the present, the panel concluded that the NLM should assume that the Internet will continue to dominate until its replacement arrives.

The panel is grateful to the Director and the staff of NLM for providing an exciting tour of the future of scholarly communication.

Donald S. Fredrickson, M.D.
Chair, NLM Planning Panel on International Programs

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The NLM Long Range Planning Panel on International Programs was chartered by the NLM Board of Regents in May 1995 for the purpose of advising NLM on the relative priority of its international activities and responsibilities, and to assist in the development of appropriate strategies consistent with the Library's statutory mission and availability of resources. The Panel was chaired by Dr. Donald S. Fredrickson; it consisted of 25 distinguished members assisted by expert consultants in the fields of medicine, telecommunications, health sciences librarianship, electronic publishing, and related fields. It met three times in 1996-7. The panel was asked to make formal recommendations to the Board on the future of NLM's international activities. The panel's recommendations reflect three overriding goals:

EXECUTIVE SUMMARY

OBJECTIVE ONE:

STRENGTHEN AND EXPAND GLOBAL ACCESS TO THE WORLD'S HEALTH-RELATED LITERATURE

1.1 NLM must expand its international partnerships with additional countries and regions that desire to benefit from improved access to electronic information resources and that seek collaborative ties with NLM, biomedical research and the medical library community. At the same time NLM must review, preferably by on-site visitation, its cooperative relationships with the present International MEDLARS Centers whose functions have been altered by the recent changes in access to MEDLINE.



OBJECTIVE TWO: CHART NEW ROUTES TO BIOMEDICAL KNOWLEDGE AND ITS USE

2.1 NLM should foster collaborative development of molecular biology information resources, such as the present GenBank, essential to the generation of new knowledge on the human genome. At the same time, the NLM must champion the open and unfettered exchange of this kind of information as essential to the health of this vital science.

2.2 NLM should actively offer its informatics expertise as a partner in research enterprises which will flourish as a result of increased communication among scientists and optimal connectivity to global information resources.



NLM serves researchers, health care professionals and patients around the world through the provision of up-to-date medical information. Representative pictures of people and places from many countries are interspersed throughout this report.

OBJECTIVE THREE: ENABLE NLM TO FULFILL ITS INTERNATIONAL MISSION

3.1 In concert with publishers, professional societies, major libraries, and international organizations, NLM should play a leadership role in the establishment of bibliographic and long-term preservation requirements and standards for electronic publications in medicine.

3.2 There being a need for well trained international workers skilled in medical informatics and the latest global information resources, NLM should actively partner with governmental and academic institutions to develop and offer such training opportunities to U.S. and foreign students.

3.3 NLM should be a prominent voice in policy debates on issues vital to the international exchange of scientific and medical information.

3.4 Additional financial resources are essential to fulfill these recommendations and to encourage the collaboration of others in their implementation.

"WITHOUT HEALTH, THERE CAN BE NO HAPPINESS. AN ATTENTION TO HEALTH, THEREFORE, SHOULD COME BEFORE ALL OTHER OBJECTS."

THOMAS JEFFERSON



Strengthen and Expand Global Access to the World's Health-Related Knowledge

INTRODUCTION

The mission of the National Library of Medicine (NLM) is to assist the advancement of medical and related sciences and to aid the dissemination and exchange of scientific and other information important to the progress of medicine and to the public health.¹ It is a two-way flow with mutual responsibilities long recognized by Congress, helping U.S. users benefit from important discoveries abroad, while

OBJECTIVE ONE

openly sharing our information resources with colleagues around the world. In the area of molecular biology, for example, information sharing using GenBank and related tools is today providing the basis for some of the latest collaborative research discoveries in gene function.

NLM builds and provides access to more than 50 electronic databases in virtually all areas of medicine and health.² MEDLINE, NLM's premiere bibliographic database, contains eight million citations to articles published in some 4,000 journals, half of which are of foreign origin.³ Foreign users account for one-quarter of the more than seven million MEDLINE searches performed in 1997. Twenty-one institutions abroad have bilateral partnership agreements with NLM (see Figure 1) that permit them to license copies of NLM's databases for searching on their own computer systems or, increasingly, link their users

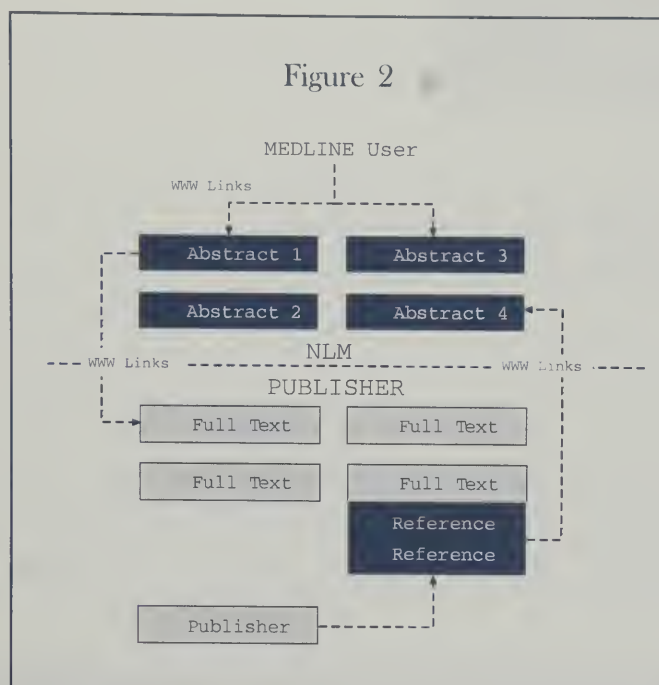
directly online to NLM via international telecommunications networks such as the Internet. These International MEDLARS Centers are located primarily in economically developed countries.⁴ International access has been further facilitated by database leasing agreements with U.S. commercial vendors.

Figure 1

NLM International MEDLARS Centers

<i>Australia</i>	<i>Kuwait</i>
<i>Canada</i>	<i>Mexico</i>
<i>China</i>	<i>Russia</i>
<i>Egypt</i>	<i>South Africa</i>
<i>France</i>	<i>Sweden</i>
<i>Germany</i>	<i>Switzerland</i>
<i>Hong Kong</i>	<i>United Kingdom</i>
<i>India</i>	<i>Pan American Health</i>
<i>Israel</i>	<i>Organization</i>
<i>Italy</i>	<i>Intergovernmental</i>
<i>Japan</i>	<i>Organization (Taiwan)</i>
<i>Korea</i>	

Figure 2



PubMed is a new MEDLINE search service developed by the National Center for Biotechnology Information (NCBI) at NLM. It has been developed in conjunction with publishers of biomedical literature as a search tool for accessing literature citations and linking to full-text journals at Web sites of participating publishers. Publishers participating in the PubMed project supply NCBI with formatted citations prior to or at the time of publication, and NCBI adds them to the PubMed database. If the publisher has a WWW site that offers full text of its journals, PubMed provides links to that site. In addition, NCBI provides a WWW Citation Matcher service, which allows publishers (or other outside users) to match up their own citations to PubMed entries, using bibliographic information such as journal, volume, issue, page number, and year. This permits publishers easily to link from references in their published articles directly to entries in PubMed.

In addition to the numerous proprietary search systems, NLM's research scientists have created a variety of user-friendly, affordable, and increasingly powerful systems for searching MEDLINE and the other databases. In 1986, the first version of Grateful Med was released, offering assisted low-cost searching to a new generation of individual users with modem-equipped personal computers. Shortly thereafter, the BITNIS gateway system was developed in collaboration with researchers at the University of Chile; it embeds a MEDLINE search within an e-mail packet envelope, thereby providing an inexpensive and fast Grateful Med search service for users in developing countries. Internet Grateful Med (IGM) was launched in 1996; it was NLM's first World Wide Web-based search service, with the added capacity to combine search terms in languages other than English.

The latest network access development occurred in June 1997 when Vice President Gore, in a well-attended press conference⁵ (see picture), inaugurated free MEDLINE searching via a new World Wide Web search engine, PubMed, and Internet Grateful Med. PubMed includes an automatic electronic gateway link to the Web sites of cooperating journal publishers, thereby offering the promise of easy access to electronic full-text journal collections, and at a lower cost than is now possible with conventional paper-based document delivery services (see Figure 2).

The panel reaffirms that NLM is a world leader in storing and disseminating biomedical scientific information. It is NLM's responsibility and obligation to the world to proffer its knowledge and expertise. Collaboration with other agencies, organizations, and institutions is



Vice President Al Gore discusses the benefits of free MEDLINE with press conference participants (from left) Suzanne McInerney (invited member of the public), Dr. David J. Lipman (Director, NCBI), Dr. Harold E. Varmus (Director, NIH) and Dr. Donald A.B. Lindberg (Director, NLM).



essential. A successful international program requires a sophisticated knowledge of the medical, economic, political, and social environments in which medical libraries operate. NLM is not apt to have such information readily available, but may be able to gain it through working with others.

FINDINGS

NETWORKING

There is a need to strengthen and expand efforts in global health information networking. These strengthened efforts should reflect changes in biomedicine, telecommunications, and related areas that lead to new imperatives. A host of factors must be considered in developing networks: political, economical, technological, cultural, and linguistic. A guiding principle is that NLM be flexible and adaptable when working out partnership relationships with foreign libraries and communities of users, and not be servant to a rigid hierarchy of rules and administrative structure.

NLM's relationship with its International MEDLARS Centers needs to change. Although originally based upon *quid pro quo* arrangements (for example the foreign center would provide indexing of local literature in

of NLM to provide search codes to their users and collect searching fees. A review of NLM's present relationships, in concert with its existing International MEDLARS Centers, in order to redefine, strengthen, or perhaps scale back their respective roles, is timely. Each should be called upon to express its intention to collaborate with NLM in some shared and mutually supportive partnership activity.

One such approach favored by the panel is the development of a loosely arrayed "network of international centers for medical information." These networked information centers may be expected to engage singly, or cooperatively, in a variety of activities in support of biomedical and health information management and access. Current International MEDLARS Centers could choose to become members of this network, which

**"THERE IS A NEED TO STRENGTHEN AND EXPAND EFFORTS
IN GLOBAL HEALTH INFORMATION NETWORKING."**

exchange for database access), very few countries now provide indexing to NLM. Consonant with the recommendations of the Planning Panel, free web-based searching has been extended to international users, and user registration requirements have been eliminated. This has led to a lessened need for the centers on behalf





would include additional members from the public and private sectors. Some countries may, at their option, choose to be represented in this network by a single institution, others by several independent or cooperating entities, or by regional confederations such as the Pan American Health Organization (PAHO) in Latin America and the Caribbean. Some institutions may elect to collaborate with NLM on activities of mutual interest beyond database access, including user education and training, outreach and R&D. These network members would have the further designation of working with NLM as “international partners,” reflecting a more intensive collaborative relationship with NLM. NLM might convene annually by invitation an advisory panel of selected network members, always including the international partners.

Targets of opportunity to be sought include new partnership relationships in countries and regions that offer particularly good prospects for benefiting from improved access to electronic information resources, and from closer ties to the U.S. biomedical research and medical library communities. Primary consideration may be

given to increased NLM involvement with the U.S.’s NAFTA-partners Canada and Mexico. In addition, other countries should be considered for possible extra efforts by NLM to extend the cooperative medical information network. Priority in the consideration should go to countries that demonstrate willingness to embrace officially the principles of sharing and participation that the MEDLARS network has always demanded, nations where we can identify active, informal, and effective local collaborators for new electronic telecommunications systems, and geographic areas whose need for improvement in health care and scientific biomedical work can clearly benefit from improved information connectivity. The availability of local people who are capable of accurately assessing needs and are committed to implementing effective and sustainable solutions is a principal requirement.

Throughout its deliberations, the Panel has sought to adhere to the principle that its recommendations be “non-NLM centric,” especially as they pertain to global networking in general and, more specifically, to the voluntary confederation of international centers of medical information. Nevertheless, NLM is in a strong position to exercise leadership such that a level of intercommunication can be achieved for the distribution and sharing of information that might not otherwise be possible if left to evolve by chance.

RECOMMENDATION 1.1

Expand NLM’s international partnerships with additional countries and regions.



DATABASES

It is neither feasible nor desirable for NLM to index all of the world's biomedical literature, including the regional and local literatures which have considerable value to local health professionals in languages other than English.⁶ At the same time, it is important that significant information generated in developing countries (e.g., about drug resistant tuberculosis and malaria) be collected, organized and made accessible throughout the global community. NLM can play a vital role in ensuring that this information is accessible electronically — both locally and globally by those who would use it, and that librarians in national and regional libraries abroad receive the necessary training and support to establish and maintain regional bibliographic compilations which eventually may be searched throughout the global community through World Wide Web links or gateways.⁷



New publication forms will increasingly become a hallmark of today's World Wide Web technology and its successors. Many excellent print journals already offer electronic counterparts. In many cases, the electronic versions contain more information than the print versions. In addition, new primary journal publications appearing only in electronic form will gain increasing prominence due to the economies of paperless distribution. Extended discourse in the form of reader commentary appended to electronic publications offers yet a new means to enhance and expand the scientific communications process. Yet, given the vast disparity in quality and authenticity of health-related information that is already apparent on the World Wide Web, new criteria for establishing linkages by NLM to external sources will be required.

The establishment of World Wide Web links to new publication forms such as primary publications appearing only in electronic form is a major opportunity that will benefit international science. Selecting web sites that NLM should link to could take into account membership of the site owner in the network of international centers of medical information, and NLM's evolving experiences with the PubMed system and its linkages to remote web sites.

DOCUMENTS

NLM has collaborated with the librarians in the U.S. National Network of Libraries of Medicine (NN/LM), to establish a North American automated document locating and requesting system, DOCLINE.



Cover of Europe, magazine of the European Union, February 1997

Currently approximately 3 million documents, mostly photocopies of articles, are provided each year by the health sciences libraries in the U.S. and Canada. These libraries maintain accurate records of their journal holdings, enabling the system to automatically route requests for a journal article to a library acquiring that journal title. NLM has offered limited DOCLINE access to the current International MEDLARS Centers willing to forward requests from a particular region or country after ensuring that the document was not available locally. Five of the Centers are accessing DOCLINE. In addition to requesting documents, page images of the articles can be sent electronically to the requesting library, obviating the use of slow postal systems. It seems worthwhile for NLM to explore the utility, difficulty, and benefits of extending the DOCLINE service to additional nations or areas, if any wish to try this experiment.

There are other important sources of document delivery, such as the British Library, which maintains a loan and photocopy service to organizations and individuals throughout the world. Ariel, developed by the Research Libraries Group (RLG), is a widely used tool that libraries, document delivery services, and other sources use to deliver documents. Using commercially available hardware and the Ariel software, users can scan articles, photos, and similar documents, and transmit the resulting electronic images over the Internet to other Ariel workstations.

Increasingly, primary journal publishers will produce electronic versions of current issues and backfiles, thus affording an opportunity for users to obtain copies on a pay per view or subscription basis from online digital libraries. NLM's PubMed system and others like it are ideally positioned to serve as a convenient means for identifying and accessing needed documents in electronic form. Such electronic document delivery services will become an important adjunct to DOCLINE. Direct electronic access to full text will substitute in many cases for paper copies of the article. Acceleration of NLM's efforts to link the PubMed system to the widest possible

array of scientific and medical journal publishers, consistent with appropriate quality standards, will be of immense benefit to the international health community.

LANGUAGE

Increasingly, English is being used for formal scientific communication. However, there is also considerable value to the local clinician in having access to local and regional information sources in his/her own language. The Unified Medical Language System (UMLS)⁸ is intended to assist the clinician in searching biomedical databases in the user's native language. Experiments have begun in which MeSH index terms are entered with



non-English equivalent terms in Spanish, Portuguese, French, and German. The situation warrants careful study to determine if these new systems improve the availability of information about local health issues and conditions as well as internationally produced health-related information for the local practitioner. Also, NLM might encourage the development of foreign language translations of its MeSH vocabulary as part of the UMLS initiative in order to allow easier use of its online services and information resources by the global community. Where appropriate, NLM could identify and collaborate with its international partners to develop non English lexicons and lexical programs to support the development of UMLS applications for non-English speakers.



Chart New Routes to Biomedical Knowledge and Its Use

INTRODUCTION

From research laboratories to the patient bedside, biomedical knowledge is being generated at a staggering rate. This new knowledge must be captured and disseminated in order for it to be useful and to make a difference to patient well-being. In addition to the traditional forms of knowledge, the use of the computer has enabled scientists to take even greater leaps into the production of knowledge, most notably through molecular biology.

OBJECTIVE TWO

The challenge is in finding new approaches to deal with the volume and complexity of data and in providing researchers with better access to analysis and computing tools to advance understanding of our genetic legacy and its role in health and disease. As the function of genes is understood, this knowledge can be put to work in the prevention and treatment of disease. Our understanding of DNA, the foundation for explaining life phenomena and the organizing principle upon which knowledge can be stored and represented, is the basis for the "new biology" which is revolutionizing international science and medicine.

These achievements in genome structure provide a challenge to the Library to participate in and perhaps facilitate the assemblage of other databases, containing information emerging from other realms of the biological or physical sciences. Some of the new knowledge generated could include three-dimensional projections

affording insight to opportunities otherwise eluding perception. Just as molecular biology has flourished, so will cell biology and neurobiology benefit from useful arrays of receptors, membranes and other cell system components, for other systems of data collection, and comparisons are already leading to better solutions of stubborn medical and social problems.

We are also generating new knowledge whose utilization may have enormous implications for preventing and controlling infectious diseases. For example, recognizing the recent advances that have been made in high throughput DNA sequencing and their application to sequencing the genomes of bacterial pathogens, investigators from the U.S. and the U.K. are now planning coordinated efforts to sequence the genome of *Plasmodium falciparum*, the parasite responsible for three million malaria deaths per year (mostly children) in Africa alone.⁹



No one may assume that the microbes, viruses, and other causes of infectious disease will alter their incessant adaptation for survival in the coming millennium. Emerging and reemerging infections, including zoonoses (diseases transmitted from animals to humans) will continue to cause threatening outbreaks or epidemics that are by no means limited to remote parts of the world. The great number of Americans traveling throughout the world today, as well as immigration of people from around the world to the U.S., combine to make the U.S. vulnerable to such diseases as antibiotic-resistant tuberculosis as well as more exotic infections such as malaria, plague, and encephalitides.¹⁰

Diagnosis, treatment, and epidemiological understanding of infectious disease often require a global mobilization of expertise and resources to save lives and avoid spread. Science policy makers at the highest levels¹¹ have urged closer international collaboration to

improve worldwide disease surveillance, reporting and response. Communications technology and networking among members of the world's global scientific community can help foster this needed cooperation and speed the flow of vital information.¹²

"FROM RESEARCH LABORATORIES TO THE PATIENT bedside, biomedical knowledge is being generated at a STAGGERING RATE. "

Disaster and emergency relief situations could be helped enormously by the application of modern communications and informatics technologies. Health professionals and other emergency workers in the field are frequently unable to obtain information they need to take care of victims. Capacity building to prepare for emergency situations and real-time information assistance during an actual disaster are both important. A number of organizations are currently involved in information support for emergencies; NLM's participation would be a useful contribution.

Recently developed image data sets and tools illustrate the potential of imaging technology to help advance biomedical knowledge. The Visible Human project, for example, permits a more detailed representation of the human anatomy and has spawned a wide range of innovative applications in research, teaching, and clinical decision-making. The Visible Human creates new knowledge with a multiplier effect that leads to further knowledge generation. At the same time, this creates ever larger amounts of image data, and the need for advanced technologies to transmit, store, and manipulate these data. Results from this and other projects-in the U.S. and abroad-suggest that the technological tools are at hand or being developed, and that the impact is likely to help transform knowledge across all areas of biomedical research and with intensified levels of international collaboration.



FINDINGS

THE NEW BIOLOGY

In the past two decades, the ability to isolate and compare the structure of individual genes has revolutionized biology, opening the gateway to far greater understanding of life in molecular terms. In a worldwide endeavor, construction of the map of the entire genome of man, consisting of an estimated 100,000 genes, including their chromosomal locations, is underway; 22% are already mapped, including genes for Alzheimer's disease, breast and colon cancer, and neurofibromatosis.

The data collection and analysis is being carried out by an International Nucleotide Sequence Database Collaboration, comprising GenBank¹³ at NLM's National Center for Biotechnology Information in Bethesda, the

DNA Databank of Japan and the European Molecular Biology Laboratory in England. The collections also include a steadily growing map of the genome of species other than man, as well as abnormal (mutated) genes responsible for many of the thousand examples of clinical diseases and syndromes linked to chromosomal abnormalities. A major milestone in molecular biology and the Human Genome Project was achieved in 1997 with the addition of the one billionth base to GenBank. This achievement reflects the explosive progress of molecular biology in understanding the genetic blueprint and paving the way for exciting breakthroughs for science and medicine in the 21st century.

The International Nucleotide Sequence Database Collaboration has been a remarkable example of the benefits of unfettered international collaboration in the exchange of scientific information. The gene sequence information collected and disseminated by the U.S., U.K. and Japanese centers is acknowledged by scientists worldwide as the scaffolding upon which the molecular biology and the practice of medicine for the 21st century will be built. In recognition of the importance of this data for breakthroughs in the understanding and treatment of human disease, foreign centers have recently made major funding commitments to enlarging their roles as informatics hubs. Even developing countries in Asia and the Pacific Rim are investing heavily in biotechnology.



"IN THE PAST TWO DECADES, THE ABILITY TO ISOLATE AND COMPARE THE STRUCTURE OF INDIVIDUAL GENES HAS REVOLUTIONIZED BIOLOGY, OPENING THE GATEWAY TO FAR GREATER UNDERSTANDING OF LIFE IN MOLECULAR TERMS."



NLM has already achieved the reputation of being the premier site for assembling, integrating, and disseminating gene data from laboratories worldwide. Each day NLM's computer systems average over one million hits from the World Wide Web and are accessed by over 30,000 users. The database is doubling every 14 months and ever-growing numbers of users depend on its content. In order to maintain its role in support of gene research in universities and in industry, the NLM requires additional support (comparable to the foreign centers) of \$10 million annually. This commitment will ensure that NLM can continue to be the key resource it has been for the past nine years and can maintain its leadership in the genome revolution.

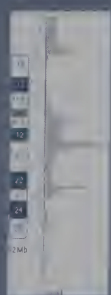
The evidence that certain genes have been conserved throughout the development of many animal species has been a spectacular revelation of evolution. The extension of analyses has provided insight into the variation in the genomes within a given species that emphasizes the uniqueness of every member of a species, including the human. Soon the databases will begin to generate knowledge of how the expression of each gene regulates the process of development of the embryo to the full being and follow the processes of growth to aging and death. Within this spectrum of understanding lie secrets of adaptation and malfunction, health and disease.

The study of the genome is a cogent example of how new knowledge can be generated through the collection of data from workers around the world, carefully arrayed and subjected to analyses, and the results then made freely available to a user in any location of the world with a connection to the Internet. The rate of harvest of new understanding through such studies will be unprecedented in human history. NLM's pivotal role in the development of molecular biology information resources is worthy of expansion, in view of the promise of this area in understanding, prevention and treatment of disease. Not only must the extension of the work on the genome be fully supported, but it is likely that the achievements in molecular genetics will be duplicated in other disciplines.

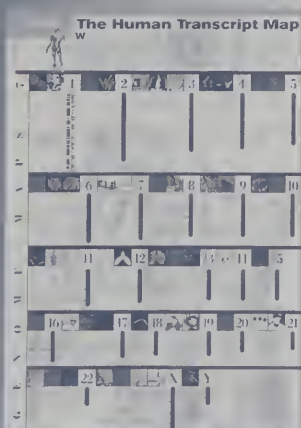
For Immediate Release:
Thursday, October 24, 1996

"Human Gene Map" to be Launched
on the World Wide Web

International Project to
Greatly Accelerate Research
and Expand Public Understanding
of Genetic Disease



BRCA1 Mutations



RECOMMENDATION 2.1

FOSTER collaborative development of molecular
biology information resources.

Detail of Breast Cancer Gene from Human Gene Map: The BRCA1 gene
maps to chromosome 17.

THE NEW BIOLOGY

Among the sciences, biology is currently the most exciting and fastest moving. New discoveries abound and the molecules and processes essential for life are being uncovered daily around the world. Much of this activity is driven by concerns for human health and medicine is a major beneficiary. The intellectual underpinning for further discoveries and their practical exploitation is now clear. Truly we stand on the brink of a revolution that presents both opportunities and challenges for all involved. As the premier repository and disseminator of biomedical information, the NLM has a singular role to play.

Since the discovery, in 1944, that DNA was the genetic material, a series of elegant and far-reaching discoveries have highlighted its central role in life. The genes present within DNA encode the proteins and RNA molecules that catalyze life's processes. By analyzing the functions and interrelationships of these products of DNA, we are building a secure foundation for understanding of all biological processes, from biochemistry through physiology and ultimately to human behavior and thought. Finally, we have grasped the importance of identifying and characterizing each of these genes within the organisms that we study. We know at the most detailed molecular levels that many genes are shared among the various forms of life on this earth. Even the simplest organisms that cause infectious diseases have genes that are demonstrably similar to ones that are so essential to our own lives. Because of this we have been able to make great strides in understanding the functioning of human genes. A major initiative is the Human Genome Project, which will soon elucidate the complete genetic complement for many organisms, including humans. For the first time we will document the complete set of components necessary for our own functioning. A massive effort is underway to collect and catalog these genes and to assign them functions. As the home of GenBank, the NLM is already a major player in this vital activity.

While the opportunities presented by the new biology for human health are immense, the explosion of information in this area presents enormous challenges. Within the research community the challenge is to comprehend the wealth of information encoded within the three billion base pairs of human DNA. Imagine the delicious complexity that enables this relatively simple molecule, DNA, to define arms, legs, eyes, the neural circuits of the brain and then permit the vast range of human behavior. But it will not be sufficient to decode just a single human DNA molecule. Rather, we must also catalog the many differences between individuals that lead to the wonderful diversity that make life on earth so interesting.

Dr. Richard Roberts,
Research Director, New England Biolabs



INFECTIOUS DISEASES

Significant targets of opportunity exist for NLM to support the generation of new knowledge in infectious diseases^{14,15} and to aid in its utilization by scientists and workers in the field. Investigators in basic research need access to genetic sequence databases, such as NLM's GenBank, and sister resources maintained in the U.K. and Japan. Developers of new vaccines, drugs and diagnostics need access to discussion groups for product development work and coordination of clinical trials. A fundamental requirement is access to the various published literatures identifiable through computer databases such as MEDLINE. NLM's new PubMed system

These opportunities in infectious disease are presently being explored by NLM in concert with NIH, as part of a larger multilateral scientific effort to strengthen collaborative biomedical research efforts in Africa, where malaria is having a profound negative impact on public health and national development. NLM is undertaking activities that will help establish an appropriate information infrastructure at the Malaria Research and Training Center in Mali, the pilot project site, so that the

"Significant targets of opportunity exist for NLM to support the generation of new knowledge in infectious diseases and to aid in its utilization by scientists and workers in the field."

supports Internet access to an increasing number of electronic versions of printed journal articles, a most valuable tool where remote and underfunded library resources are poor. Epidemiologists engaged in vector control and surveillance programs use geographic information systems (GIS) and satellite-based remote sensing technologies; it is highly desirable that collaborating units maintain contact through electronic mail and other electronically mediated means of communication that are becoming increasingly possible over the Internet. New modes of communication and publication, particularly electronically linked World Wide Web sites, provide a central means for identifying and networking with fellow researchers, and accessing related scientific resources.



malaria research community may have access to the Internet and needed information resources, including electronic mail, databases and repositories, and published scientific literature. This pilot project may serve as a model for other NLM contributions in Africa and elsewhere. Active NLM support of efforts by NIH and other interested world bodies to strengthen



MALARIA IN AFRICA:

AN EXERCISE IN COOPERATION, SUPPORT, AND COMMUNICATIONS

DAKAR, Senegal—Three million deaths per year (mostly children), one death every 20 seconds, and a punishing impact on the health and economy of Africa. This is the cost of malaria as a re-emergent infectious disease in Africa. Traditional means of malaria prevention and treatment are failing due to drug resistance, insecticide resistance, and new and dramatically different patterns of disease transmission. In a landmark conference held in Dakar, Senegal in January 1997, 125 malaria experts from 35 countries, 50 from 22 African countries, came together to seek means to strengthen and sustain, through collaborative research and training, the capability of malaria endemic countries in Africa to carry out research to develop or improve tools for malaria control. One pressing need: to enhance the capacity of African scientists to communicate electronically with colleagues in Africa and the North, and to access needed scientific information from local libraries, remote databases and on the Internet. At a follow-up meeting held in The Hague, Netherlands, in July 1997, NLM accepted the challenge to pursue this communications objective in concert with NIH colleagues, and as part of the Multilateral Initiative on Malaria (MIM).

collaborative biomedical research efforts in infectious diseases and the utilization of newly generated knowledge, through improved access to communications technology and networking resources, is critical to the improvement of health. NLM will need to be able to engage in international outreach missions for fact-finding and planning for the purpose of identifying the local scientific communities' needs for enhanced communications capabilities in support of basic research, prevention, treatment and control. NLM may also develop the capacity to organize training missions to infectious disease research sites to help assure effective use of new communications technology, and to promote information management skills, networking and resource sharing among regional libraries. (See **Objective 3** and section on "International Training in Medical Informatics and Global Information Resources").

DISASTER AND EMERGENCY RELIEF

Another prominent opportunity in international health is disaster and emergency relief. Communications is one of the first vital services to be disrupted in a disaster. Health professionals and other emergency workers in the field are frequently unable to obtain information they need to take care of victims. Capacity-building to prepare for emergency situations and real-time information assistance during an actual disaster are both important. A number of organizations are currently involved in information support for emergencies; NLM's participation would be a useful contribution.

NLM's toxicology and environmental health databases are largely an untapped resource for emergency relief. These systems proved extremely valuable some years

RECOMMENDATION 2.2

Offer its informatics expertise as partner in research enterprises.



"COMMUNICATIONS IS ONE OF THE FIRST VITAL SERVICES TO BE DISRUPTED IN A DISASTER."



ago in efforts to cope with a disastrous chemical spill in Bhopal, India.¹⁶ NLM needs to enhance the usability and accessibility of its toxicology and environmental health databases to encourage their effective utilization in disaster relief situations, including use of their contents for the preparation of summary digests.

Numerous targets of opportunity exist for NLM to support pilot projects demonstrating and/or evaluating models that employ new wireless communications technologies, and specially crafted information management tools that may be particularly well suited for use by lesser-trained emergency workers in remote locations. Support of efforts by the World Health Organization, the Pan American Health Organization, the Federal Emergency Management Agency, the Red Cross, and others, to use modern information technologies to aid health workers engaged in public health work, particularly emergency and disaster aid relief, is an appropriate role for NLM.

IMAGE DATA SETS AND TOOLS

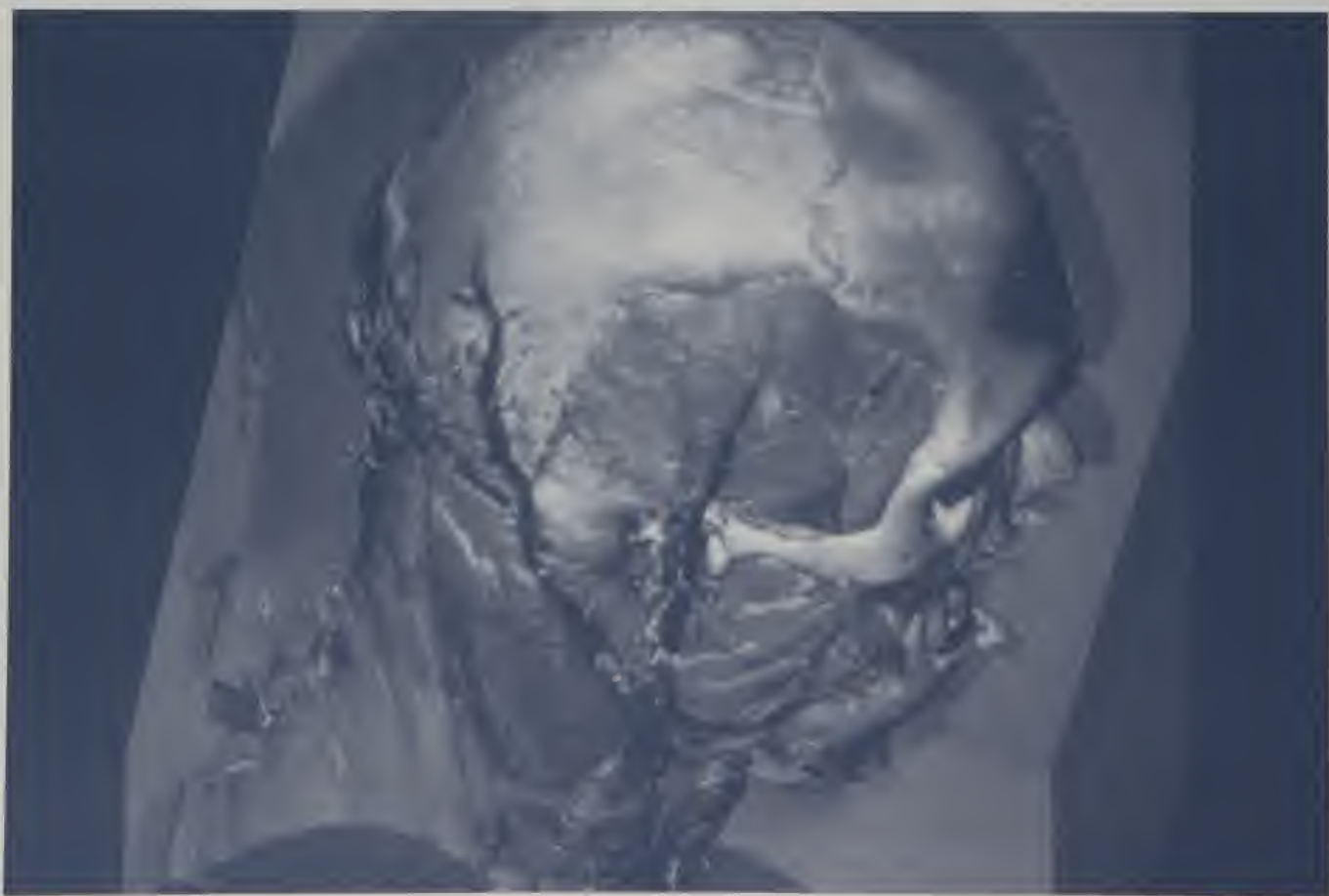
New imaging data sets and tools will help generate substantial new biomedical knowledge. The Visible Human Project¹⁷ is an outgrowth of the NLM's 1986 Long-Range Plan. It has created a complete, anatomically detailed, three-dimensional representations of the male and female human body by collecting transverse CT, MRI and cryosection images of representative male and female cadavers at one millimeter intervals.



The panel found that NLM's Visible Human project has successfully demonstrated the role of biomedical image data sets and tools in the generation and utilization of new biomedical knowledge. The Visible Human is a complete, anatomically detailed, three-dimensional digital representation of the male and female human body.¹⁸ It has its roots in NLM's long-range planning vision that foresaw a future "where NLM's bibliographic and factual database services would be complemented by libraries of digital images, distributed over high speed computer networks and by high capacity physical media."^{19,20}

The Visible Human data sets²¹ have thus far been licensed for use worldwide by some 1000 research, academic, and industrial groups in 28 countries. The images are being used for teaching, modeling radiation absorption and therapy, equipment design, surgical simulation, and simulation of diagnostic procedures, among many other applications.²²

The panel affirms the long-term goal of the Visible Human Project, which is to produce a system of knowledge structures that will transparently link visual knowledge forms to symbolic knowledge formats such as the names of body parts. NLM support of research on image data sets and tools that offer the potential of generating new biomedical knowledge, and the means to develop and use such knowledge, in collaboration with U.S. and international research partners, is a valuable contribution to international health efforts. Such research should emphasize the tools, technologies, and technical standards for creating, managing, and accessing the large-scale image data sets like those being developed by the Visible Human Project. Participation in international imaging research projects should focus on those where there are direct benefits both to the U.S. and other countries, such as the multi-language anatomical digital database project approved by the G7 Global Healthcare Applications Project national coordinators.²³





Enable NLM to Fulfill its International Mission

INTRODUCTION

Advances in communications and networking technologies, collectively, help facilitate NLM's international activities. The ongoing Internet and World Wide Web "revolution" make possible the quick, cost-effective distribution and exchange of biomedical information. Progress in telemedicine offers the promise of the cost-effective practice of medicine at a distance. NLM has always been a leader in researching and applying new technologies—typically years ahead of their wide-

OBJECTIVE THREE

spread adoption. Today, the Internet offers new opportunities for NLM to leverage its limited resources for strengthening the U.S. and global biomedical information infrastructure. But not all countries and regions of the world, or geographic areas within the U.S., are participating equally in this revolution. The playing field is not level. NLM's leadership role in monitoring and improving access to such technologies, and the information gateways they open up, among rural, remote, inner city, and other medically underserved areas is highly commendable and must be continued—both at home and, to the extent possible, through partnerships abroad.

Biomedical scientists and health practitioners worldwide are becoming increasingly dependent on computer-based tools for the conduct of biomedical research and for ensuring that patients benefit from that research. Information technology has at once become the means

for advancing the pace of scientific discovery in fields such as molecular biology and the means by which health care delivery throughout the world can keep pace with rapid advances in the laboratory. It is not enough to make information technologies available; there is a broad need for training in their use, including database searching, as well as all aspects of health sciences librarianship and medical informatics.²⁴

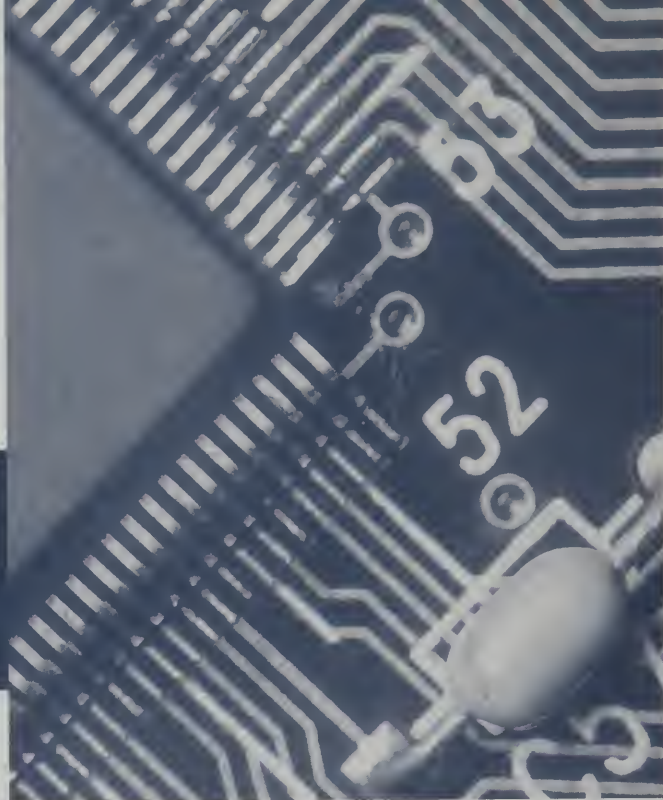
Although tremendous advances in medical information, computers, and communications have been made over the past decade, many parts of the world do not have access to these technologies and services. It is important for libraries and other institutions and organizations throughout the world to work to extend modern biomedical information services to everyone. NLM can not do this in a vacuum from its headquarters in the U.S.; participation of a global "field force" is essential.

The global information infrastructure is now widely recognized as an essential component of international health care and biomedical research, along with international business, trade, and tourism. Information policies that affect the biomedical realm now have a strong global dimension—telecommunications and information systems

“ADVANCES IN COMMUNICATIONS AND NETWORKING TECHNOLOGIES, COLLECTIVELY, HELP FACILITATE NLM’S INTERNATIONAL ACTIVITIES

do not stop at national boundaries. Thus it is imperative that the NLM and other leading U.S. biomedical information organizations take a vigorous role in the global information policy arena. Failure to do so could compromise U.S. national interests and the needs of the U.S. and international health and biomedical communities.

NLM will benefit from partnerships with international organizations such as the World Bank and the World Health Organization, and U.S. government agencies including the Centers for Disease Control, the Department of State, and NASA. Private sector organizations, including commercial entities, foundations, and philanthropies such as the Burroughs Wellcome Fund and the Wellcome Trust, are also important examples of potential collaborators for the purpose of evolving complementary strategies for sharing health-related information and improving world-wide access to it.



The 1987 NLM Long Range Plan recommended that the Library “Provide assistance to other countries in identifying and gaining access to biomedical information in the U.S. Also assist U.S. health-care professionals in accessing information developed outside this country.”²⁵ The panel unequivocally affirms the fundamental imperative of this recommendation. Yet, NLM needs to augment and leverage its financial resources to support such an activity without distorting or impeding its domestic program objectives. None of the recommendations of this report can be carried out without resources—funding and staff in particular. Although the panel strongly believes that NLM can not accomplish the goals of this report without the active collaboration of those in the public and private sectors in many countries around the world, it also recognizes that augmentation of NLM resources will be necessary.

“INFORMATION TECHNOLOGY HAS AT ONCE BECOME THE MEANS FOR ADVANCING THE PACE OF SCIENTIFIC DISCOVERY IN FIELDS SUCH AS MOLECULAR BIOLOGY AND THE MEANS BY WHICH HEALTH CARE DELIVERY THROUGHOUT THE WORLD CAN KEEP PACE WITH RAPID ADVANCES IN THE LABORATORY.”

NEXT GENERATION INTERNET

I envision the day when today's early telemedicine experiments, dependent on specialized equipment and expensive communication lines, will have evolved so that the Internet becomes the standard vehicle for linking medical experts with other clinicians and patients at a distance...I envision the day when I can prescribe for my patient a specially-selected video educational program that will be delivered...by a direct Internet connection...Health science schools will similarly provide distance-learning experiences...We clearly need high [transmission] speeds, but many applications will fail to be effective or accepted if the quality of that bandwidth is also not adequate...How do certain kinds of applications obtain guaranteed, reliable transmission speeds? How do we assure interoperability across the many networks? How do we assure the necessary bandwidth is available not only on the major backbone networks, but also on the last segment of wire, cable, or wireless network that comes into our homes and offices? We do not know. There is a clear agenda that must be tackled and that motivates the NGI.³⁵

Dr. Edward H. Shortliffe
Professor of Medicine
and Computer Science
Stanford University



FINDINGS

COMMUNICATIONS AND NETWORKING TECHNOLOGIES

The panel found that the advent of facile means to distribute scientific information quickly, accurately, and without geographic constraints (as exemplified by the World Wide Web and Internet), is rapidly expanding access to information throughout society. It



is critically important for NLM to actively encourage the development, availability, and use of advanced communication and networking technologies, including telemedicine applications^{26,27,28} for the benefit of U.S. and global health researchers, practitioners, and consumers. This should include efforts to upgrade equipment platforms and Internet connectivity at medical libraries and other health-related institutions in developing regions of the world.

The panel discussed the possibility of an opportunity for establishing a worldwide virtual network or presence on the Internet. The advent of the Internet and the existence of a growing body of technologies make such a network technically possible and economically feasible. The existing network of International MEDLARS Centers, medical libraries, and medical schools provides a natural collection of sites. "Last mile" links from libraries, medical schools, and other institutions to the local Internet nodes would be provided by local private sector or cooperative efforts, possibly with the support of NLM and other international collaborators in priority areas, as is planned in the African malaria initiative. The placement of the nodes should be made with consideration given to the information needs of potential users.

The statistics on growth of the Internet²⁹ highlight both the opportunities and challenges of using the Internet for global biomedical information applications. On the one hand, the Internet Society and various Internet experts have documented the exponential global increase in the number of Internet users and host computers. But many countries and vast regions of the planet are still without affordable Internet access. In support of NLM's international activities, periodic evaluation of the quality and connectivity of the Internet among NLM and its domestic and international partners would enable NLM to maintain an up-to-date understanding of trends and problems in global Internet connectivity.

The panel concluded that potentially, Internet applications such as the World Wide Web and especially its electronic publishing capabilities (see section below on Electronic Publishing), can help close the gap between the information access of richer and poor nations. The WWW is, increasingly, a form of electronic publishing, especially with regard to obtaining research or clinically relevant biomedical information from geographically

and organizationally diverse sources. The Internet and WWW can provide resource-limited and currently underserved nations with an ability to access and share biomedical information that is not available to them today. Some of these nations believe that the Internet can help them leapfrog ahead into the electronic information arena and overcome the limitations of seriously incomplete or obsolete traditional paper-based medical libraries and information services. Intensified partnering, leadership, and investment of financial, technical, and human resources will be necessary in order to achieve this.

In addition to facilitating access to the Internet, there is much research and development to be done. NLM's participation in the Next Generation Internet (NGI)³⁰ provides a source of both funding opportunities and technology support for extending networking experiments to include biomedical research collaboration and information exchange.³¹ NLM needs to be in the forefront of World Wide Web experimentation and application, including use of the WWW for new forms of information exchange and discourse on biomedical topics, and for the creation and utilization of new knowledge.

Finally, the panel concluded that telemedicine³² has evolved to the point where it now represents a significant health care opportunity. NLM has been involved in telemedicine research and applications since the late 1960s, spanning several areas of activity, including: bibliographic and research databases; sponsored research programs;³³ high performance computing and communications; grants programs; and internal research.³⁴ Collectively, these activities give NLM a strong basis for international collaboration in telemedicine. For example, information is critical to medical decision-making in the telemedicine context.

ELECTRONIC PUBLISHING

The ability to search, annotate, and share both textual and graphical information, and to distribute it to select recipients or the world at large have changed the rules of academic publication. The availability of vast amounts of searchable quality information opens new channels of scholarship in analysis of trends, analyses of comparable data sets and other opportunities for scholarship yet to be discovered. Publishers may perceive threats to their print products even as they search for distinctive ways to offer newer and better services to their authors, editors and readers. All publishers, whether for-profit or not-for-profit, have perceived the welcome options inherent in electronic publishing of reducing and controlling paper and postal costs. As the primary indexer and announcer of biomedical literature, it is important for NLM to work with professional societies and publishers to establish a standard notation to indicate definitive publications that will be bibliographically controlled and accepted into the scholarly record.

<http://www.sciencemag.org/>

SCIENCE ONLINE

Special access to the Mars Pathfinder foldout, including the martian surface panorama from the lander in 3D, and an overview of the Mars Pathfinder mission in a Report by Golomhek et al.

Science - Browse & Search full text, special features & data, Tech.Sight & Access Information for Libraries

ScienceNow - Daily news

Science's Next Wave - Free access: News, forums, columns on career development in science.

Science Professional Network - Free access: Job listings, career fairs & other resources

Electronic Marketplace - Free access: Product Information, Advertiser Directory, & Reader Service



RECOMMENDATION 3.1

Establish bibliographic requirements and standards for electronic publications in medicine.

INTERNATIONAL TRAINING IN MEDICAL INFORMATICS AND GLOBAL INFORMATION RESOURCES

NLM has an important role to play in providing training opportunities, both directly and by encouraging its international partners and others to provide training. Several promising strategies are being explored as a basis for a joint partnership with the NIH Fogarty International Center (FIC). Pre- and post-doctoral students from low- and middle-income nations would receive training grants enabling them to study at NLM-sponsored academic institutions currently offering such training to U.S. students. The fundamental goal would be to develop information specialists and educators who can apply information technologies to biomedical research and health care delivery around the world. Courses of study could be tailored to the medical informatics needs and capabilities of the home country. Other international organizations engaged in health professional training, such as the Wellcome Trust in the United Kingdom, could augment their programs to include a medical informatics component.

Similarly, there should be opportunities for interested U.S. students to obtain training in medical informatics

as part of their studies abroad. The NIH Office of Minority Research and the FIC are supporting the establishment of a "guest house" for African-American and other students to study at the Malaria Research and Training Center in Bamako, Mali. Funding could also be provided to enable these students to pursue additional training in medical informatics, particularly in those skills needed to assist African scientists and information specialists in obtaining reliable and sustained access to electronic global information resources. NLM can encourage U.S. academic institutions with programs of study abroad to support informatics training for students engaged in international development work, capacity building, and outreach. Some U.S. institutions have formalized cooperative partnerships with sister institutions abroad.

RECOMMENDATION 3.2

Develop and offer training opportunities to U.S. and foreign students.

GEORGIA-GEORGIA COOPERATION

An example of an international venture into training people in the use of information technologies for medicine may be found in the partnership between Emory University (Atlanta, Georgia) and the Republic of Georgia. The National Information Learning Center (NILC) in Tbilisi serves as a national medical library and provides extensive and intensive training to health professionals and students, library and computing professionals, scholars and teachers in the use of networked resources. Its mission is to promote the application of emerging technologies in information management, health education and communication throughout Georgia, and to provide:

- access to MEDLINE and other biomedical databases and full text files through Emory University,
- an in-house collection of print and CD ROM resources covering the breadth of biomedical topics,
- a basic collection of multi-media resources,
- document delivery services by mail, e-mail or fax, and
- training in the use of networked resources, including e-mail.





POLICY

The panel concluded that globalization of the world's economy and the central role of information technology and services mean that the U.S. must take cognizance of global information policy issues. This is necessary to assure that resolution of those issues is equitable and balanced with regard to both U.S. and foreign interests. The G7, Organization for Economic Cooperation and Development, UNESCO, and various other international bodies have identified the global information policy arena as vital to economic development. Given the rapid increase in international business, trade, tourism, and travel, global health information policy is increasingly important.

Indeed, the panel found that there is a critical need for NLM and the biomedical information community to have a "place at the table" in deliberations that may affect international health information policies. A case in point is the proposed database protection treaty that was considered by the World Intellectual Property Organization in December 1996. Biomedical and other science information research and user groups were not involved in the development of the proposal, and only at a late date learned that the proposal could place serious restrictions on the free flow of scientific information. Due in part to concerns raised by the scientific community, the proposal was deferred for further revision.³⁶ This experience highlights the importance of involving the biomedical scientific community in all stages of policy development—from issue identification to agenda setting to policy studies and ultimately the development, consideration, and adoption of specific policy options.

The panel concluded that NLM needs to give special attention to several information policy issues as they relate to biomedical information. These include intellectual property; privacy and confidentiality; security;

freedom of information/public access; archiving; and a range of technical issues such as standards-setting and interoperability. Open access and exchange must, of course, be balanced by strong protections for the privacy and confidentiality of any personal information that might be involved, and for the assurance of a level of technical security that protects such personal information from unauthorized or illegal disclosure or use. But at the core, the panel believes that NLM must serve, as it has in the past, as a strong advocate for the open exchange of biomedical information as fundamental to scientific advancement, research progress, and, ultimately, improved medical practice and better informed health care practitioners and consumers. NLM is already involved to varying degrees in all of these issues. For example, NLM's sponsorship of the National Research Council's study on medical information privacy is noteworthy and commendable. The resulting report provides substantial policy analysis and options that are relevant to international as well as domestic biomedical information privacy deliberations.³⁷

NLM is a member of the U.S. Government's Committee on Computing, Information, and Communications—a subgroup of the National Science and Technology Council—and thereby positioned to participate in the debate and resolution of issues relevant to domestic and international large scale networking and high-end computation, including the evolution of the Next Generation Internet. Additionally, many relevant policy issues are being addressed within the context of the G7 Global Healthcare Applications Project, for which the NLM Director is the U.S. coordinator.³⁸

RECOMMENDATION 3.3

SPEAK OUT ON ISSUES VITAL TO THE INTERNATIONAL EXCHANGE OF SCIENTIFIC AND MEDICAL INFORMATION.

RESOURCES

The current organization and staffing of NLM's international programs is split among several organizational units and takes advantage of the unique capabilities and interests of each. The International Programs Office, located in the Office of Health Information Programs Development, has overall policy responsibility which it should retain. Operational responsibilities are shared among various NLM divisions, including Library Operations, the Office of Computer and Communications Systems, and the National Center for Biotechnology Information whose international relationships are playing an increasingly pivotal role in the furtherance of the new

biology. International activities require constant special attention, planning, implementation, and operations. Additional full-time, highly qualified, and experienced staff is required to provide the best opportunity to achieve a successful program. Moreover, greater participation by NLM's international partners and collaborating institutions will further the implementation of this report's recommendations.

RECOMMENDATION 3.4

Additional financial resources are essential

THE NATIONAL MEDICAL LIBRARY OF ARMENIA

An example of an effort to develop a National Medical Library can be found in Armenia. There, the Ministry of Health, through its Republican Scientific Medical Library (RSML), is creating a National Medical Library with the assistance and support from the Fund for Armenian Relief and the Samuel J. Wood Library/C.V. Starr Biomedical Information Center of Cornell University Medical College. The mission of the RSML is to collect, organize, and provide access to biomedical information.

The RSML has developed a basic collection of print biomedical materials and provides extensive training to health professionals and librarians in the use of information technology for access to biomedical information. The Library has obtained several grants to establish a computer teaching laboratory and has developed a telecommunications network of several hospitals and health care organizations that provides access to the Internet and the Library's home page. In addition to educational programs and support for access to information, the Library also provides English as a second language classes for Armenian health professionals and is the WHO Documentation Center for Armenia. The Library has taken a leadership role in Armenia both in training health and information professionals as well as in developing a national biomedical resource and the network for accessing it. Major accomplishments have been made in developing a telecommunications network and in training other librarians and health professionals in using computers.

RECOMMENDATIONS OF THE PANEL

OBJECTIVE 1: STRENGTHEN AND EXPAND GLOBAL ACCESS TO THE WORLD'S HEALTH-RELATED LITERATURE

1.1 NLM must expand its international partnerships with additional countries and regions that desire to benefit from improved access to electronic information resources and that seek collaborative ties with NLM, biomedical research and the medical library community. At the same time NLM must review, preferably by on-site visitation, its cooperative relationships with the present International MEDLARS Centers whose functions have been altered by the recent changes in access to MEDLINE.

OBJECTIVE 2: CHART NEW ROUTES TO BIOMEDICAL KNOWLEDGE AND ITS USE

2.1 NLM should foster collaborative development of molecular biology information resources, such as the present GenBank, essential to the generation of new knowledge on the human genome. At the same time, the NLM must champion the open and unfettered exchange of this kind of information as essential to the health of this vital science.

2.2 NLM should actively offer its informatics expertise as a partner in research enterprises which will flourish as a result of increased communication among scientists and optimal connectivity to global information resources.

OBJECTIVE 3: ENABLE NLM TO FULFILL ITS INTERNATIONAL MISSION

3.1 In concert with publishers, professional societies, major libraries, and international organizations, NLM should play a leadership role in the establishment of bibliographic and long-term preservation requirements and standards for electronic publications in medicine.

3.2 There being need for well trained international workers skilled in medical informatics and the latest global information resources, NLM should actively partner with governmental and academic institutions to develop and offer such training opportunities to U.S. and foreign students.

3.3 NLM should be a prominent voice in policy debates on issues vital to the international exchange of scientific and medical information.

3.4 Additional financial resources are essential to fulfill these recommendations and to encourage the collaboration of others in their implementation.



IMPLEMENTATION STEPS

In particular, funding is needed to support the following high priority initiatives:

- Enhancement of the resources of the National Center for Biotechnology Information to assure that it will continue to compete effectively and to collaborate on an equal footing with its international counterparts in Europe and Asia;
- New collaborative activities leading to establishment or enhancement of international health Internet nodes and networks to provide means for conducting research and distributing and sharing biomedical information in the form of high quality World Wide Web services and value-added communications capabilities;
- Active participation in the Multilateral Initiative on Malaria to enhance the capabilities of African scientists to engage in malaria research and control efforts by improving communications capabilities, promoting information management skills, and networking and resource sharing among regional libraries;
- Evaluation and reconfiguration of the International MEDLARS Centers program, including the formation of an advisory group, to support the development of new collaborative working relationships in the medical and technological domains addressed in this report;
- New training and educational opportunities for foreign and U.S. students;
- Enhanced computer, communications, and basic library services necessary to support NLM's expanding international programs.

It is estimated that an additional \$20 million annually will be needed to initiate these new international collaborations and programs.

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MEDICAL INFORMATICS (DECEMBER 1995)

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ENDNOTES

¹ The National Library of Medicine Act (1956) states, "In order to assist the advancement of medical and related sciences, and to aid the dissemination and exchange of scientific and other information important to the progress of medicine and to the public health, there is hereby established in the Public Health Service a National Library of Medicine (hereinafter referred to in this part as the "Library")." The Library is directed to acquire and preserve books, periodicals prints, films, recordings, and other library materials, pertinent to medicine; organize those materials by appropriate cataloging, indexing, and bibliographical listing; publish and make available catalogs, indexes and bibliographies; make library materials available, through loans, photocopy or other methods; provide reference and research assistance; publicize the availability of NLM's products and services; promote the use of computers and telecommunications by health professionals; and engage in such other activities as appropriate and the Library's resources permit.

² Examples include MEDLINE, TOXLINE, AIDSLINE, and GenBank.

³ In MEDLINE in 1966 there were 174,553 citations from 2,419 journals, 53% of which were to biomedical literature written in English. Thirty years later, in 1995, 350,898 articles, editorials, and letters were indexed from 3,774 journals; 88% were in English.

⁴ For over two and one-half decades, the National Library of Medicine has entered into bilateral agreements with public institutions in foreign countries to serve as International MEDLARS Centers. NLM's intent is that these Centers assist health professionals in accessing MEDLARS databases, offer search training, provide document delivery, and perform other biomedical information support functions. Under current policy, to

be designated by NLM as an International MEDLARS Center, the institution must be nominated by the country's highest health official and meet several other criteria.

⁵ NLM NEWSLINE, March - August 1997, Vol. 52, No. 2-4.

⁶ Approximately 29% of the substantive biomedical journals currently published throughout the world are included in MEDLINE.

⁷ Examples of such databases are the African Index Medicus and Lilacs covering literature from Central and South America.

⁸ The Unified Medical Language System (UMLS) Knowledge Sources are freely available to international researchers and system developers, and there are UMLS users and applications throughout the world. The 1996 edition of the UMLS Metathesaurus contains the French, German, Portuguese, and Spanish translations of the Medical Subject Headings (MeSH), which are produced by various International MEDLARS Centers. Over the next several years, NLM expects to add additional MeSH translations, e.g., Chinese and Japanese. Because Internet Grateful Med makes use of the Metathesaurus, it can support searching in these languages.

⁹ Malaria Genome Working Group: Burroughs Wellcome Fund, Wellcome Trust, National Institute of Allergy and Infectious Diseases (NIAID), Department of Defense (DoD), Malaria Foundation

¹⁰ See Institute of Medicine Report, *America's Vital Interest in Global Health: Protecting Our People, Enhancing our Economy, and Advancing our International Interests*. (Washington, DC; National Academy Press, 1997)

¹¹ National Science and Technology Council's "Committee on International Science, Engineering and Technology" (CISET), a group led by CDC, the Department of State, USAID, FDA, NIH and DoD, has recommended that the U.S. Government work with other countries, WHO and with other international organizations

¹² Taped interview of David Heyman, Director, Division of Emerging and Other Communicable Diseases, World Health Organization, for the second meeting of the Long Range Planning Panel on International Programs, March 11-12, 1997.

¹³ GenBank is an annotated collection of all publicly available DNA sequences. There were approximately 843,000,000 bases in 1,275,000 sequence records as of April 1997. A new release is made every two months. On the order of one-third of the data contributions come from abroad and international scientists comprise a similar fraction of the thousands of those who consult the database monthly.

¹⁴ Institute of Medicine, *Emerging Infections: Microbial Threats to Health in the United States*, 1992.

¹⁵ National Science and Technology Council, Committee on International Science, Engineering, and Technology, Working Group on Emerging and Re-emerging Infectious Diseases, *Infectious Disease—A Global Health Threat*, 1995.

¹⁶ Murray KM, Meth B. Methemoglobin, MEDLINE, and hyperlipemia. *Critical Care Medicine* 1987 Aug;15(8):797-8).

¹⁷ The conference proceedings are available on CD-ROM. See Richard A. Banvard and Michael J. Ackerman, eds., *The Visible Human Conference Proceedings, October 7 & 8, 1996* (Bethesda, MD: National Library of Medicine, 1996, on CD-ROM). Presentations covered, for example: virtual anatomy; simulation of human joints;

three-dimensional anatomical library; digital cadaver; digital brain atlas; 3-D model of a female pelvis; virtual endoscopy; and distribution and viewing of Visible Human images over the World Wide Web.

¹⁸ Information on NLM's Visible Human Project can be found at <http://www.nlm.nih.gov>.

¹⁹ NLM Fact Sheet, "The Visible Human," on the web at <http://www.nlm.nih.gov>.

²⁰ In early 1989, at the direction of NLM's Board of Regents, the NLM Long Range Planning Panel on Electronic Imaging recommended that *NLM should undertake a first project building a digital library of volumetric data representing a complete, normal adult male and female. This Visible Human Project will include digitized photographic images for cryosectioning, digital images derived from computerized tomography, and digital magnetic resonance images of cadavers.*

²¹ The male data set includes axial MRI images of the head and neck and longitudinal sections of the rest of the body all taken at 4 mm intervals. The male data set also includes axial CT scans of the entire body and anatomical cross-sections all at 1 mm intervals. The female data set is the same, with one exception—the axial anatomical images were taken at 0.33 mm rather than 1.0 mm, resulting in over 5,000 anatomical images for the female compared to 1,871 for the male.

²² Projects include the VOXEL-MAN Atlas developed by the University of Hamburg, and Human Anatomy Visualization, developed by the Center of Information-enhanced Medicine—a joint venture of Johns Hopkins University and the Institute of Systems Science of the National University of Singapore.

²³ The anatomical database project is intended to take advantage of the inherently word-free and language-neutral Visible Human images by adding multi-lingual anatomical labeling. The same concept applies to data-

bases developed by other countries. Ultimately, multi-lingual databases will increase the accessibility and utility of these databases to U.S. and international biomedical researchers.

²⁴ National Library of Medicine (US), Board of Regents. Long range plan; Report of the NLM Long Range Planning Panel on the Education and Training of Health Science Librarians. Bethesda (MD): The Library; 1995 Jan.

²⁵ National Library of Medicine (US), Board of Regents. Long range plan. Bethesda (MD): The Library; 1987 Jan., recommendation 2.2.7.

²⁶ Examples of telemedicine projects include a consortium of nine institutions led by the Concurrent Engineering Research Center of the West Virginia University, demonstrating the viability of secure clinical telemedicine on public telecommunication networks and showing that its adoption as an integral part of an overall health care plan can result in cost savings and improved access to quality health care for rural populations; the use of telemedicine by Beth Israel Deaconess Medical Center in Massachusetts to provide educational and emotional support to families of high risk newborns both during their hospitalization and following discharge; and the use of telemedicine by Columbia University to provide information to patients that will improve disease prevention activities and effectively manage chronic illnesses in the home setting,

²⁷ Institute of Medicine. Telemedicine: A Guide to Assessing Telecommunications in Health Care, 1996.

²⁸ National Research Council. For the Record: Protecting Electronic Health Information, 1997.

²⁹ NLM's surveys of the existing International MEDLARS Centers found that, as of 1996, almost all were using the Internet to a significant extent, and most had some type of presence on the World Wide Web. Globally, the number of Internet users has increased from about one million in January 1990 to over 60 million today. Like-

wise, the number of host computers on the Internet has risen from about 200,000 in January 1990 to over 16 million today. At current growth rates, the number of Internet users would equal the total world population very early in the 21st century. Some tapering off of the growth rate therefore normally would be expected, but the Internet may defy conventional wisdom. Notwithstanding these optimistic trends, Internet accessibility is very uneven worldwide. According to the Internet Society, the number of countries with Internet access—defined as a full point of presence, not just dial-up—increased from 96 in mid-1995 to 134 in mid-1996. However, 103 developing nations were still without Internet access. These were located primarily in Africa, the Middle East, South and Southeast Asia, the Caribbean, and Oceania. Also, many nations listed as having Internet access have widely variable access—sometimes limited to the capitol or major cities, with limited or no access or very costly access in the rest of the country. Experts advising this panel have noted that Internet access is still limited to nonexistent in much of Central and South America, Eastern Europe, and the former Soviet republics, as well as in the areas noted above. In sum, Internet is still much more a promise than reality for much of the world, with a wide disparity in access generally favoring the more industrialized and economically stronger nations.

³⁰ Testimony on The Next Generation Internet, Edward H. Shortliffe, MD, PhD, Professor of Medicine and of Computer Science, Associate Dean for Information Resources and Technology, Stanford University School of Medicine, before House Committee on Science, September 10, 1997.

³¹ NLM should define its role in international health information networks in consultation with potential collaborators, including international medical libraries and biomedical information providers, and other international organizations with an interest in supporting healthcare information infrastructure improvements. The networks would provide: a means for distributing

and sharing biomedical information among points of presence (POPs), in the form of high quality World Wide Web services; Internet-based communications services that support telephone, fax, and high value-added services such as teleconferencing; and a capability to support biomedical and medical informatics teaching and training using advanced techniques such as multicasting.

³² Telemedicine has been defined by NLM as the use of telecommunications and computers for: 1) the provision of information that supports medical decisionmaking; 2) signal processing, e.g., physiologic samples, such as electrocardiography, blood pressure measurement, or ultrasound, or image signals, such as video presentation of x-ray, skin surface, or patient visage; and 3) the arrangements between persons and institutions that make it possible to practice medicine at a distance. See Donald A.B. Lindberg and Betsy L. Humphreys, "Computers in Medicine," *Journal of the American Medical Association*, Vol. 273, No. 21, June 7, 1995, pp. 1667-1668.

³³ NLM co-sponsored a U.S. Institute of Medicine study on telemedicine evaluation. The resulting report is being used as a framework for evaluation of NLM-supported domestic telemedicine projects, and is relevant to international telemedicine projects as well. See Institute of Medicine, *Telemedicine: A Guide to Assessing Telecommunications in Health Care* (Washington, DC: National Academy Press, 1996).

³⁴ Information on NLM's National Telemedicine Initiative can be found at <http://www.nlm.nih.gov>.

³⁵ Excerpted from statement of Dr. Edward H. Shortliffe before the Committee on Science, U.S. House of Representatives, hearing on the Next Generation Internet, Sept. 10, 1997.

³⁶ Bits of Power: Issues in Global Access to Scientific Data, Committee on Issues in the Transborder Flow of Scientific Data, U.S. National Committee for CODATA,

Commission on Physical Sciences, Mathematics, and Applications, National Research Council, 1997.

³⁷ National Research Council, Computer Science and Telecommunications Board, *For the Record: Protecting Electronic Health Information* (Washington, DC: National Academy Press, 1997).

³⁸ The G7 Global Healthcare Applications Project is made of seven sub-projects. Sub-project 1, "Towards a Global Public Health Network" investigates the feasibility of linking existing and emerging public health data telematic networks in Canada, Europe, Japan, the USA, the World Health Organisation, as well as other international health-related organizations. The main challenge is to ensure that the systems are inter-operable across the world. User friendly, fast, cost effective systems hold the key to success. Sub-project 2, "Improving Prevention, Early Detection and Treatment of Cancer", aims at establishing multimedia databases which will enable health professionals across the world to seek decisional support for patient management and referral. Each participating center should be responsible for compiling and updating information, for one or more multimedia databases, on specific aspects of the disease. Sub-project 3, "Improving the Prevention, Diagnosis and Treatment of Major Cardiovascular Diseases" aims at establishing centers of excellence providing teleconsultation services and access to multimedia databases. Peripheral centers and health professionals should then be able to access the best possible information and expertise. The centers of excellence should also receive information on the long-term follow-up of patients from peripheral centers and medical partners. Sub-project 4, "A 24-hour Multilingual Telemedicine Surveillance and Emergency System Around the World" could provide the basis for a 24-hour multilingual emergency teleconsultation service. This service could benefit a wide range of people including those at sea, travelers, people working in isolated places and those living in regions with less developed healthcare services. Sub-project 5 "Enabling mechanisms for global healthcare

network” aims to identify the most efficient tools and communication infrastructure for accessing and navigating the networks. It should also focus on linguistic aspects—such as on-line translation—and the harmonisation of security standards for patient related data exchange. Sub-project 6 “International harmonisation of use of data cards in healthcare” aims at ensuring: the harmonisation of data sets and the interoperability of applications and services by complying with relevant international standards; the complementarity and synergy between data cards and telematics networks; and the acceptability to society by meeting demands for privacy and security. Sub-project 7 “Evidence and effectiveness”—During the G-7 meeting in Rome in May 1996, Canada made a proposal for a new sub-project called “Evidence and effectiveness” (based on the Janus Web-compatible publishing system in Canada), where evidence-linked information is delivered to the point-of-care, while at the same time enabling the retrieval of patient-related information from the point-of-care which contributes to updating the published information.

³⁹ Bush, Vannevar. *Science, the Endless Frontier. A Report to the President by the Director of the Office of Scientific Research and Development*, United States Government Printing Office, Washington: 1945.

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